Having a child with a disease like cystic fibrosis is unimaginably hard. Barely a waking hour has gone by since my son's diagnosis that I haven't thought about it. CF is a terrible disease: there is no known cure and the average life expectancy is just 37. My son can't digest most foods, he is susceptible to lung infections by bacteria that exist everywhere (like in standing water and dirt), and he is most likely sterile. He does chest therapy and breathing treatments for 1½ to 5 hours a day. There are no support groups for families with CF, because of the risk of cross contamination. The closest pediatric pulmonologist, who we see every three months, is based in Great Falls—a mere 250 miles from our home.

But I should go back and introduce myself. My name is Jill Hansen-Twardoski and my son Derek is 2 ½. I would like to tell you how we got where we are today, and why I am HERE today.

When Derek was born, he was at the 50th percentile in weight and height; that is he was a perfectly average sized newborn. He breastfed well but didn't gain weight like he should. When he started daycare at three months old, he began to have a persistent cough and permanent nasal congestion. At a time where most kids are sleeping through the night, he was breastfeeding for up to three hours each night. As first time parents my husband and I were concerned and took him to our family practice clinic six times in three months, or about every other week. We knew something wasn't right. Finally after Derek got pneumonia and had a respiration rate at nearly four times average, we were recommended to follow up with a pediatrician. She diagnosed cystic fibrosis immediately. Derek was eight months old.

By this time he was seven pounds lighter and four inches shorter than average. His failure to thrive in combination with his lung problems was a textbook case of CF. What we learned after Derek's diagnosis is that my husband and I both unknowingly carried the CF gene. One in every thirty one Americans carries a CF gene and one in every three thousand babies is born with CF. I know that's only three or four babies a year in Montana but the health issues for kids with CF are bad enough without being exacerbated by a late diagnosis. You can google article after article supporting this point. Children with CF who do not have an early diagnosis are shorter, have more hospitalizations, and are not as healthy as those who get immediate treatment.

The regimen we were placed on was extreme, due to the level of damage and infection in Derek's lungs and his position on the growth chart—or I should say OFF the chart. The black line is the 50th percentile, or average height and weight for a baby boy. The orange line follows Derek's actual measurements. We gave him percussions and multiple nebulized breathing treatments every four hours around the clock. He was instantly placed on two antibiotics (including Cipro, what they give to people with anthrax), a bronchodilator, a mucus thinner, enzymes, and extra vitamin supplements. He was already infected with a bacteria in his lungs that took eight months to get rid of. His oral antibiotics made him throw up and the nebulized antibiotics took an extra hour an a half every day. We administered chest therapy three or four times a day where we had to beat on our baby's chest to physically loosen clogged mucus from his lungs.

CF has affected every decision my husband and I have made in the past two years. First of all, I gave up breastfeeding so he could have both an extra calorie formula and a special easy-to-digest formula which was much more expensive than the regular stuff.

Second, my husband was in the middle of changing jobs and suddenly it didn't matter where he wanted his career to go, all that mattered was where we could get the best health insurance. Third, I quit my senior-level accounting job to stay home and care for our boy. And finally, our family's everyday routine completely revolves around fitting in his therapies and being constantly vigilant about germs.

The problem in Montana is that what happened to Derek and to us could happen to anyone. My husband and I are responsible, college-educated parents with health insurance and our son was literally starving to death for eight months under a doctor's constant care. The suffering he went through is unconscionable and it is your responsibility to protect future Montanans from this unnecessary pain. Family doctors and nurse practitioners, especially in small towns, need more help diagnosing diseases like CF.

In conclusion, I can't emphasize enough what a difference an early diagnosis would have made for Derek's health. This is not the face of a healthy eight month old boy. But with his breathing treatments and digestive enzymes, and even though he has CF, he is a very healthy two year old. I know there will be a cure for CF in Derek's lifetime, and my family raises a lot of money each year for the Cystic Fibrosis Foundation. But medical research is slow and we need to take action RIGHT NOW to protect our most precious resource—the next generation of Montanans. Every child born in Montana needs to be screened for CF.

It hasn't been easy for me to write this speech and relive the terrible and needless suffering that Derek went through. But I am here because I think our story can make a difference. Each of you has the opportunity to make a difference to future parents just

like me and get kids like Derek off to a much better start in life. The newborn screening program MUST be expanded. So it costs $10 per baby to screen for CF? Don't you think I would've paid a thousand or a million times that to not watch my son starve?

Jill Hansen-Twardoski

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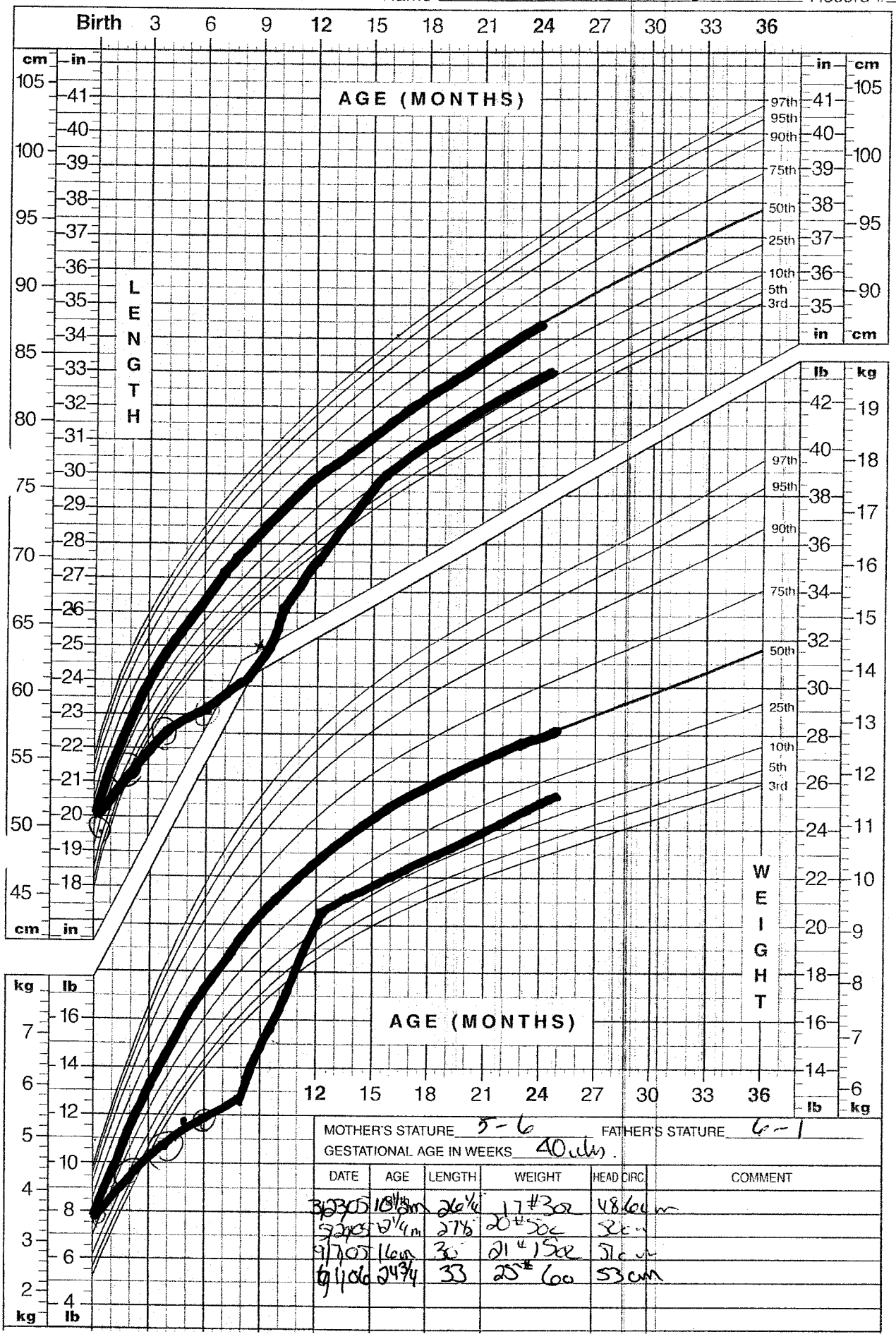
BOYS: BIRTH TO 36 MONTHS
CDC US GROWTH CHARTS*

Name Derek Twardoski Record # 188273



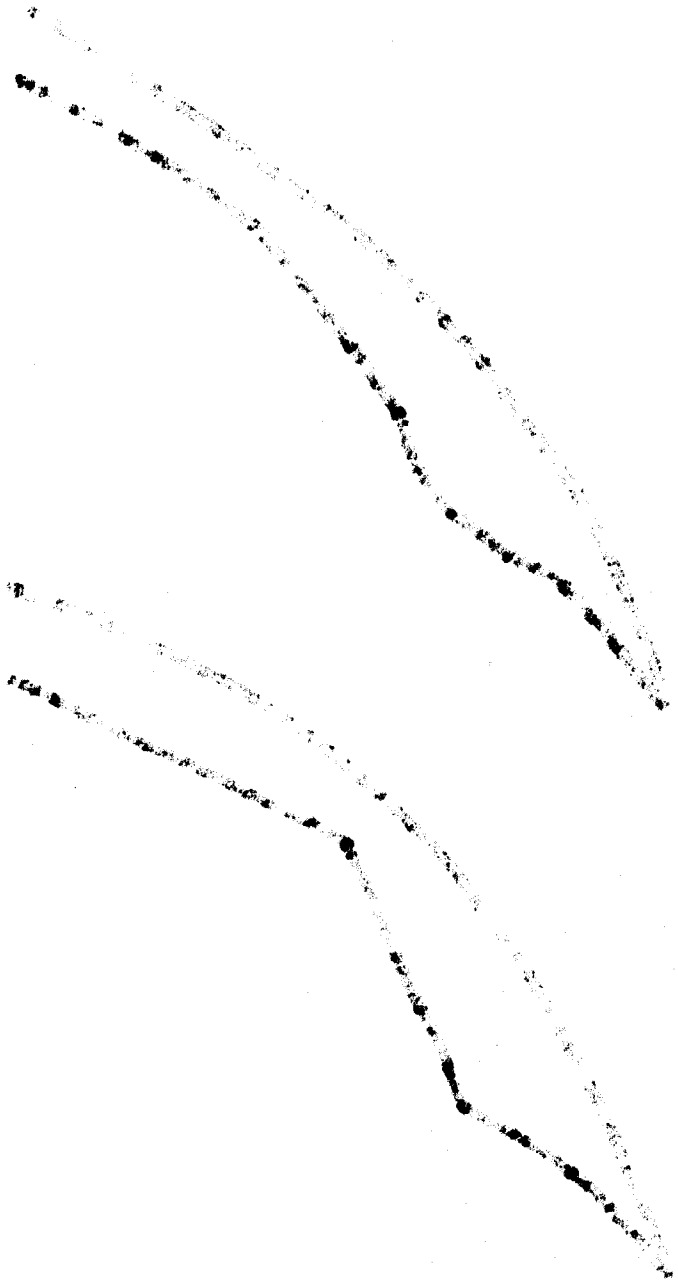
MOTHER'S STATURE 5-6 FATHER'S STATURE 6-1

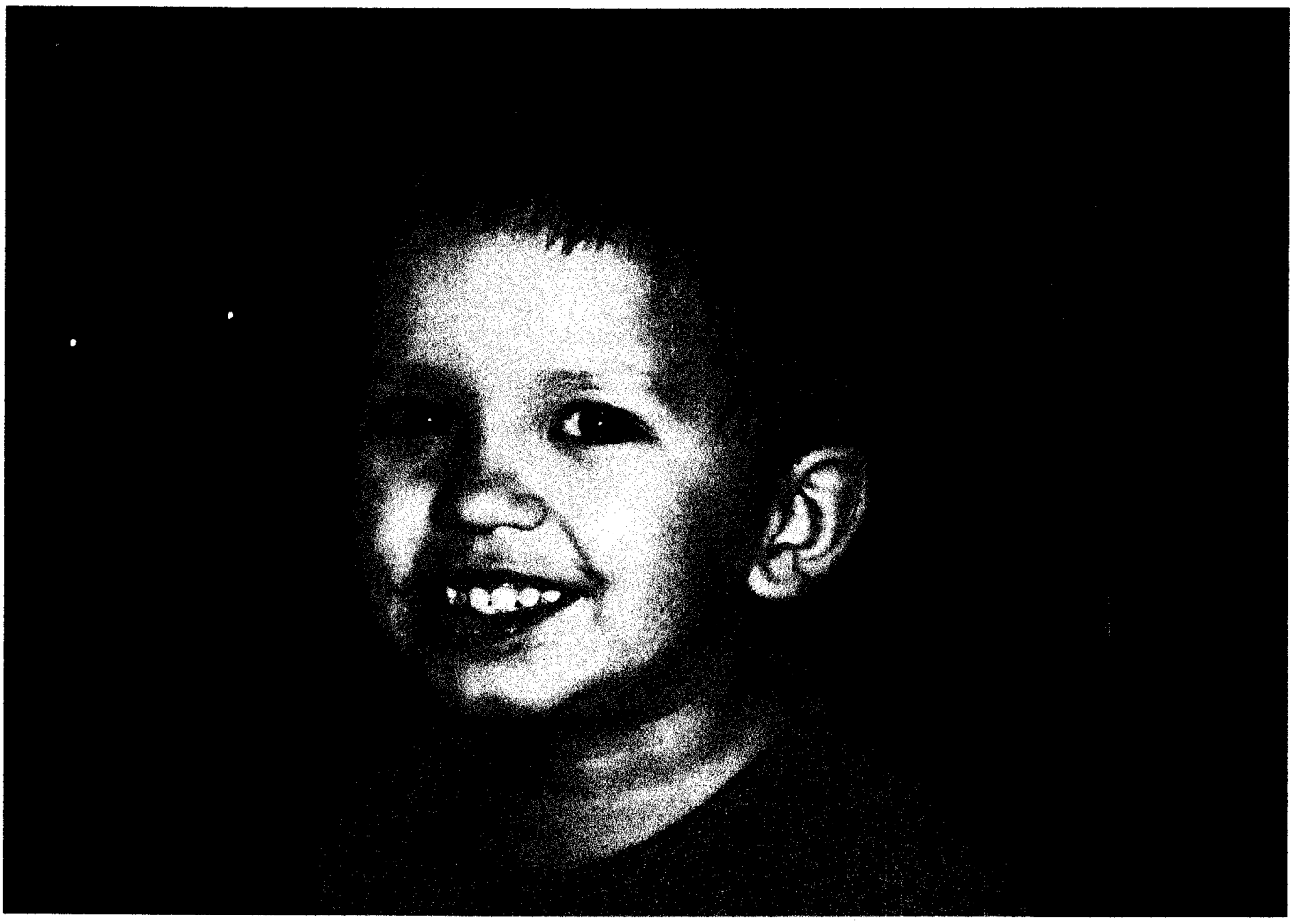
GESTATIONAL AGE IN WEEKS 40 wks.

DATE	AGE	LENGTH	WEIGHT	HEAD CIRC	COMMENT
3/30/05	10 1/2 hrs	26 1/4"	7 lb 3 oz	48.6 cm	
4/20/05	21 1/4 m	27 1/2"	20 lb 5 oz	52 cm	
9/7/05	16 m	30"	21 lb 15 oz	51 cm	
6/1/06	24 3/4	33"	25 lb 6 oz	53 cm	

* Adapted from the National Center for Health Statistics in collaboration with the National Center for Chronic Disease Prevention and Health Promotion (2000). Kuczmarski RJ, Ogden CL, Grummer-Strawn LM, et al: CDC Growth Charts, United States. Advance data from vital and health statistics No. 314. Hyattsville, Maryland: National Center for Health Statistics, June 8, 2000.

Internet: www.cdc.gov/growthcharts





REUTERS

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Screening may improve cystic fibrosis outcomes

Mon Jan 15, 2007 9:25 PM GMT

NEW YORK (Reuters Health) - Individuals with cystic fibrosis (CF) who are identified through newborn screening have improved growth, better overall health, and require fewer long-term therapies than those who are identified later in life when symptoms appear, new research suggests.

CF is a genetic disease involving thick mucus secretions in the lungs and pancreas. Patients with the disease are prone to pneumonia and other complications and have an average lifespan of about 30 years.

Screening newborns for CF is a controversial topic because it is unclear if this approach ultimately improves pulmonary function. However, the studies that have investigated this topic have not accounted for differences in the treatments given to "screen-detected" versus clinically diagnosed patients.

Dr. Erika J. Sims, from the University of East Anglia in Norwich, UK, and colleagues compared outcomes for 990 CF patients, between 1 and 10 years of age, who were identified through newborn screening, or were diagnosed clinically within the first 2 months of life (early-clinically diagnosed), or were diagnosed clinically after 2 months (late-clinically diagnosed).

According to the team's report in the journal Pediatrics, patients identified through screening were taller, generally healthier, and required fewer long-term therapies than late-clinically diagnosed patients. Early-clinically diagnosed patients typically had outcomes similar to their screen-detected peers.

"Patients with cystic fibrosis diagnosed by symptom presentation after the age of 2 months manifest worse clinical outcomes despite receiving higher levels of long-term therapy for at least the first 10 years," the authors conclude.

However, consistent with previous reports, screen detection did not significantly improve lung function despite the improved outcomes, the results indicate.

Overall, team says, "Newborn screening for cystic fibrosis provides an opportunity to maximize the clinical potential of patients whose survival may otherwise be limited to early adulthood."

SOURCE: Pediatrics, January 2007.

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CF Foundation urges all states to include newborn screening for cystic fibrosis in test panels

15 Oct 2004 Click to Print

The Cystic Fibrosis Foundation today issued a recommendation for the implementation of routine cystic fibrosis (CF) screening in all newborns. In addition, the Centers for Disease Control and Prevention (CDC) issued a recommendation in its October 15 Morbidity and Mortality Weekly Report (MMWR) Reports and Recommendations that all states should consider routine screening for CF in all newborns. CF Foundation-supported research and peer-reviewed evidence conducted and gathered over the past two decades have demonstrated the benefits of newborn screening for CF. People with CF who are diagnosed at birth gain more weight and have better nutrition than those who are diagnosed later in life. Better nutrition and weight gain in children with CF has been linked to a slower decline in respiratory function, the primary cause of death in CF.

Advances in CF treatment and care, have had a significant impact on the length and quality of life for people with CF. Research on newborn screening for CF has shown further clinical benefit when therapeutic interventions were administered near the beginning of life. Early diagnosis allows a special high-calorie, high-fat diet, along with pancreatic enzyme and fat soluble vitamin supplementation to begin immediately, if needed, before digestive complications occur. Better nutrition has been linked to improved height and weight measurements, better pulmonary status, and cognitive benefits.

"It is imperative that states add newborn screening for CF to their test panels to give people with this disease the best odds at living longer, healthier lives," said Robert J. Beall, Ph.D., president and CEO of the Cystic Fibrosis Foundation. "The CF Foundation is prepared to be a resource of knowledge and expertise for states as they consider this important recommendation and begin implementing newborn screening for CF."

Although new therapies and specialized care have extended the lives of people with CF, the average age of diagnosis–approximately 3 years–has remained the same. Traditionally, children with CF are not diagnosed unless CF has been present in a family's history or until symptoms appear. In many cases, delayed diagnosis has resulted in irreversible nutritional and pulmonary morbidities. By making a CF diagnosis sooner, therapeutic interventions can minimize and postpone the development of symptoms, which can slow the progression of the disease.

Implementation of CF Newborn Screening

Participants in a recent workshop hosted by the CF Foundation discussed how to implement routine newborn screening for CF, as well as how the CF Foundation and its nationwide network of accredited care centers can ensure the best care for newborns before classic CF symptoms develop. The CF Foundation will work closely with state governments to urge the inclusion of CF on newborn screening test panels and will provide guidance on optimum test procedures and the elements of a comprehensive program. The CF Foundation also will encourage states to refer parents of newly diagnosed infants to its accredited care centers. These centers provide state-of-the-art specialty care and the opportunity for infants to benefit from medical advances. In addition, these centers will continue to track demographic, diagnostic, and treatment data via the CF Foundation's national Patient Registry to further improve their care. Newborn screening for CF also will enable new treatment options for infants to be evaluated and developed.

"After reviewing and carefully considering the scientific evidence, the benefits of newborn screening for CF are now clear. We now must turn our attention to ensuring that parents of newborns

diagnosed with CF are given the educational resources they need to care for their children and that they receive appropriate treatment from CF experts," said Preston W. Campbell, III, M.D., executive vice president of medical affairs of the CF Foundation. "I am eager to witness the improvements that CF newborn screening will inevitably bring to people with CF and am proud of the CF Foundation's leadership role in this initiative."

The newborn screening tests for CF are not diagnostic tools. If the initial screen is positive, then further tests are done to rule out or confirm a CF diagnosis. Only a fraction of newborns with a positive initial screen ultimately will be diagnosed with CF. Currently, seven states conduct CF newborn screening in all newborns; three states screen for CF in some hospitals or populations; while two more states are now implementing CF screening programs. From 1990 to 1999, 1.46 million babies were screened for CF and 372 were ultimately diagnosed with CF. CF is one of the most common disorders identified in the newborn screening programs that include it in their testing.

Members of the media may obtain copies of the CDC's MMWR Reports and Recommendations by calling 404-639-3286. Further information on newborn screening for CF is available on the CF Foundation's Web site at Cystic Fibrosis Foundation or by calling (800) FIGHT CF.

The Cystic Fibrosis Foundation

CF is a genetic disease that affects approximately 30,000 people in the United States. A defective gene causes the body to produce abnormally thick, sticky mucus that leads to chronic and life-threatening lung infections and impairs digestion. When the CF Foundation was created in 1955, few children lived to attend elementary school. Today, because of research and care supported by the CF Foundation with money raised through donations from individuals, corporations and foundations, the median age of survival for people with CF is in the early 30s.

The mission of the Cystic Fibrosis Foundation is to assure the development of the means to cure and control cystic fibrosis and to improve the quality of life for those with the disease. For more information on cystic fibrosis, call (800) FIGHT CF or visit Cystic Fibrosis Foundation.

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